

Privacy & Security Tiger Team
Draft Transcript
November 22, 2010

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director

Good morning, everybody, and welcome to the Privacy & Security Tiger Team. This call is scheduled from 10:00 to noon. It's a federal advisory committee, so there will be opportunity at the end of the call for the public to make comments. Let me do a quick roll call. Deven McGraw?

Deven McGraw - Center for Democracy & Technology – Director

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Paul Eggerman?

Paul Eggerman – Software Entrepreneur

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Latanya Sweeney? Gayle Harrell? Carol Diamond?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Judy Faulkner? David McCallie?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Neil Calman? David Lansky? Dixie Baker? Micky Tripathi? Rachel Block?

Rachel Block – New York eHealth Collaborative – Executive Director

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Alice Brown?

Alice Brown – National Partnership for Women & Families – Director HTP

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

John Houston?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Wes Rishel?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Leslie Francis? ...?

W

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Adam Greene?

Adam Greene – Office of Civil Rights – Senior HIT & Privacy Specialist

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Did I leave anyone off?

Leslie Francis – NCVHS – Co-Chair

Leslie Francis is here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you.

Joy Pritts – ONC – Chief Privacy Officer

Joy Pritts is here.

Judy Sparrow – Office of the National Coordinator – Executive Director

And Joy. Thank you.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Dixie Baker is here.

Judy Sparrow – Office of the National Coordinator – Executive Director

And Dixie. All right. Thank you very much. I'll turn it over now to Deven.

Deven McGraw - Center for Democracy & Technology – Director

And I'm going to turn it over to Paul.

Paul Egerman – Software Entrepreneur

Good morning. It's Paul Egerman. I want to welcome you to our tiger team meeting. This is a public meeting. We want to welcome any members of the public who might be on the call. We have three agenda items that we want to discuss. This is a privacy tiger team. We want to discuss what happened. The first agenda item is we want to discuss what happened at the policy committee meeting on Friday. Secondly, Deven is going to talk a little bit about the governance presentation. Then the third thing, which is the bulk of our conversation, will be to prepare for our patient matching hearing that will be held on December 9th.

To first tell you about a presentation that Deven and I gave with our provider authentication recommendations on Friday in front of the policy committee, I would tell you that the recommendations were approved. There were basically three issues that were raised. The first issue is there were some very minor typos, so we made a few mistakes in the slides, and showing that the policy committee members showing that they were carefully paying attention and managed to find our errors, and so that was probably a good sign, especially since it was on the last slide of the Friday afternoon presentations.

The second area is a little more substantive was we had a recommendation in terms of what are the requirements to receive a digital certificate. We had said there were two requirements. One was that you had to be a valid business entity. The second one was we said you had to engage in the types of transactions involved with meaningful use.

And there was some discussion of that, and the request was made that we make that a broader statement, which would be to say that you had to be involved with health data exchange transactions, so slightly broader than meaningful use, so that was the most substantive change. And there was actually a spirited conversation about a topic that was not directly related. There was some concern expressed about what happens to information exchange when you send data from point A to point B? What level of control do you have then in terms of what point B does with it in terms of whether or not they go ahead and send it to point C further down the line? And what level of protection do you have there?

We said that was an interesting issue. It was just outside the scope of what we were addressing. We were just addressing provider authentication with this recommendation. But there was a lot of interest in that topic, and so we'll sort of forward that to ONC in terms of where that might go in our agenda. Based on that discussion though, with very slight modifications, our recommendations were approved by the policy committee, so that was a very good success for the tiger team. I don't know if you have anything to add, Deven. Does that sound right?

Deven McGraw - Center for Democracy & Technology – Director

Well, only to thank both Dixie and David in particular who gave us some helpful wordsmithing changes. It was actually in incorporating those that my editing skills fell off the wagon a bit, and that's why we ended up with a couple of typos, but I just wanted to thank them for taking the time to read through the slides and provide us with some edits.

I will say that the slide deck that you did get that I sent out Friday does have the slides with the changes that Paul mentioned that the policy committee had requested, so you have the version that was approved. Judy Sparrow turns it into a transmittal letter, which then goes to ONC so further action can be taken on them, particularly with respect to, we have a direction in there to standards to select or specify a technical standard for authentication.

Paul Eggerman – Software Entrepreneur

Before we go on to the next topic, does anybody have any comments or questions about that? Not hearing anything, Deven, do you want to start talking about governance?

Deven McGraw - Center for Democracy & Technology – Director

Sure. Both Paul and I thought it would be helpful to spend some time on our call today talking a bit about the governance workgroup recommendations because obviously the recommendations that workgroup comes up with are really almost hand in glove with some of the recommendations, if not all of them, that we make because we're dealing with substantive policy issues around privacy and security, but they are looking at mechanisms of accountability and who should be responsible for setting the rules, enforcing the rules, etc. What is the role of government? What, if any, might be the role of other bodies in an accountability infrastructure? We are fortunate to have on our call a couple of our members who are also on governance, Wes and Carol are on both -

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

What about me?

Paul Eggerman – Software Entrepreneur

John Houston.

Deven McGraw - Center for Democracy & Technology – Director

John Houston, thank you. I didn't hear you on earlier.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes. Also David McCallie.

Deven McGraw - Center for Democracy & Technology – Director

David McCallie is on governance as well?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

No. No, not me. Sorry.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'm sorry.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I listen to the call, but I'm not a member.

Deven McGraw - Center for Democracy & Technology – Director

Christine Bechtel is also on, but Alice Brown from the National Partnership is regularly on our calls to give Christine a little bit of a break. Leslie Harris from CDT is also on, but we're obviously not the same person. But there is this continuity, so I raise that only to say that I'm going to do what I hope is a summary, but I'm not going to go into too much detail because obviously there are folks on the call who know more about this than I do.

The bottom line is that the governance workgroup presented a very comprehensive set of recommendations that the policy committee asked to be able to consider them to hold off on making the decision. There were a lot of questions that were raised during the policy committee meeting. We were not ready, as a group, to adopt some at our meeting and have asked for the governance workgroup to do a bit more work and to give them to us in chunks, in sections, divide it up a bit so that we can have a more complete discussion about sort of each sort of – a smaller set of recommendations versus necessarily trying to grasp them all in just one two-hour session, and I believe they are amenable to that. I think they had thought that they were under some time deadlines with respect to getting a rulemaking out, but after the policy committee, I think that there is a sense that there's a way to do this to get more feedback from the policy committee, as well as the public, to get some buy in on a structure that, an accountability infrastructure that folks are very comfortable with before moving to the rulemaking process. There'll be more on this. I think, Judy, are the slides now up on the...?

Judy Sparrow – Office of the National Coordinator – Executive Director

I just sent an e-mail to the Web people. Evidently there's an error message, but we're working on it.

Deven McGraw - Center for Democracy & Technology – Director

I'm sure they'll get that resolved. Once they're up on the Web, you may want to take a look at them because this is a very comprehensive deck of slides that they've been working through. In general, there were sort of three components to their recommendations. One was a federal role, a role for the federal government to play that involves setting what they called conditions of – I thought it was conditions of participation, but now I forgot what the TI stood for.

Alice Brown – National Partnership for Women & Families – Director HITP

...interoperability.

Deven McGraw - Center for Democracy & Technology – Director

Thank you. Conditions of trust and interoperability—thank you, Alice—that are the sort of set of policies and standards that create trusted and interoperable exchange, and the federal government plays a role in setting them, coordinating federal activities, and overseeing governance of the Nationwide Health Information Network, which is the NW-HIN, as opposed to just the NHIN. But they also recommended that there was a nongovernmental role that could provide support for implementing these conditions of trust and interoperability that includes identifying implementation issues and making recommendations to the federal government and obtaining input from a broad range of stakeholders, which includes consumers, but isn't limited to just consumers. And then there was a third role, which was a validation

role, which would involve at least one private sector entity to validate or verify whether these conditions are being met, verifying compliance, addressing issues with noncompliance, and there would be at least one of these entities, but potentially delegated to multiple others with the idea being you could validate as a provider yourself as sort of meeting these conditions of trust and interoperability with one of these validators, but you wouldn't have to go to multiple ones. You'd only need to go to one, but that this was very different from certification, which is about the equipment, the EHR as the software.

There were these sorts of three buckets, lots and lots of questions about who would play this validation role. What would be involved in the validation role? What are the characteristics and attributes of entities that would play this role, as well as the non-government role? Where are the lines to be drawn between what's the responsibility of the federal government? Is this an infrastructure of accountability that works given that much of it is voluntary? Not obviously whatever the federal government sets in law, but that it's almost like not exactly a brand that one subscribes to, but creating sort of consent of the governed type of arrangement where you create an environment of trust in fact by agreeing to participate, and then you can hold yourself out as participating in accordance with these conditions of trust and interoperability. And, in doing so, others who know that you are part of this infrastructure or ecosystem can therefore trust that you abide by certain baseline conditions and exchange with you.

I'm not sure I explained this terribly well. What I wanted to get across was this sort of three-pronged nature of those recommendations. Before I get myself into any more trouble, I'm going to stop. Paul, I want to give you a chance to react, but also the other members of the governance workgroup in particular and, of course, other members of the tiger team to react. There will be many more opportunities to weigh in on this, I think, the important bottom line is that this is still a work in progress. That it was a very interesting presentation by the governance workgroup of what I know what a lot of very hard work and lots of phone calls.

Paul Egerman – Software Entrepreneur

That's very good, Deven. I actually have some comments on this, but I'd rather let the tiger team members talk first, especially since some of them are members of the group, to say whether or not Deven gave a complete....

Deven McGraw - Center for Democracy & Technology – Director

Yes, I know I didn't.

Paul Egerman – Software Entrepreneur

In other words, if they have something they want to add or if they have any comments. I didn't mean to say it, but that's the way it came out.

Deven McGraw - Center for Democracy & Technology – Director

No, it's okay. I can't say that I totally understand all of it. It's an incredible body of work.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I thought Deven did a pretty good job considering, as I say, the complexity of it, and she was trying to summarize. I think it's probably worth understanding that the challenge associated with governance is changing and challenges when they change generally don't get smaller. It's changing in a couple of ways.

One is that there's this incredibly complicated interaction between about a fairly complicated set of issues around the way government organizations can interact with private organizations when it comes to sharing data. The second is that this started out and the operating model that we have now is for governance of the exchange of information among health information exchanges, not within them, and with the expansion of the notion of the concept formally known as the NHIN. The scale of it gets to be considerably larger. Overall, I would say that this team is struggling with how to – I think some of us thought, well, we've already got a working model. We're just going to have to sort of bless it and tweak it a little bit to make it applicable outside of where government contracts are involved, and we're done. It hasn't turned out to be that way.

Paul Eggerman – Software Entrepreneur

That's a very helpful comment, Wes. This is Paul Eggerman. When you started talking, Wes, I was going to remind you and everybody to say your name when you speak for the people on the public on the call. But your comment, Wes, was certainly one of my observations, which is this is a lot more complicated than I realized when I started listening to it. Governance is a pretty complicated subject.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

Paul Eggerman – Software Entrepreneur

I think the other – I'm sorry. Go ahead. Was that Carol?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, Paul. Sorry. I tried to speak earlier and disconnected myself. I didn't hear Wes' comment, but I would say that in terms of being complicated, I think one of the challenges that we also had is that we were trying to have these conversations in very short periods of time. I think, very often, people had different ideas about some of these issues. In other words, they heard them differently or envisioned something differently. Because there wasn't enough time to really discuss those deeply, I think we ended up in a place where there were just too many questions.

Even on the issue of "validation", as Deven was describing it, as a member of the team, I never understood that to really make a decision about whether both trust and interoperability had a private sector validation role, even in the recommendations. There was some discussion about for things like interoperability that there may be, and questions, quite frankly, about how it was different from certification, that there may be a role. But we never really were able to get deeply into the issues.

I guess what I would say was that the outcome, I think, speaks to the quality of the process, which is to say that I think we do need to chunk the discussion, and we do need to dive deeply into each of the area and really discuss what it means in very specific ways. One of the things I was going to actually suggest would help us is also, if you think about some of the recommendations that would come from the tiger team or that have come from the standards committee or the policy committee, and think about them in the context of governance so that we can use them to trigger some of the specificity, I think, that's necessary to be able to sort through what are a set of very complicated issues.

Paul Eggerman – Software Entrepreneur

Helpful. Other comments?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes. This is Dixie Baker. I have a question. Wes almost got to it, but not quite. That is, can you give me a better understanding of the difference between NW-HIN and NHIN?

Paul Eggerman – Software Entrepreneur

I think it's the W.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

No, it's the notion. This is Wes. It's the notion that rather than the NHIN being a few hundred large entities that are intercommunicating using the policies and standards approved through NHIN governance, it applies to a much broader range of intercommunication, including the things that are called NHIN Direct.

Judy Faulkner – Epic Systems – Founder

Wes. This is Judy. How do we pronounce it now?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Well, we don't even know what it is. That is, all we really know is that there is a new name pending that will come from ONC some time this year. NW-HIN was just our attempt to sort of acknowledge that point without making a big deal about it in every presentation. I don't think NW-HIN would pass the scrutiny for avoiding the trademark violation myself, but I'm not a lawyer.

Judy Faulkner – Epic Systems – Founder

Okay.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

What you're saying, I think, is that NHIN has come to mean an exchange among federal agencies, and this would be federal and private.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

No. NHIN, as conceived under ... and rolling forward through all of the trial implementations to where it's actually operating now is an exchange among governmental and private entities, but the governance was designed well enough to get through the trial implementations, but under the assumption that the governed bodies were a relatively small group of very large organizations. So the Indianapolis HIE or the Virginia HIE or Kaiser or the VA or the sort of kinds of organizations that were conceived sitting at the table last February, ONC rolled out what was called NHIN Direct, and is now called the Direct Project, and chose to label it as a part of the NHIN. In so doing, it expanded the number of participants and the number of use cases it had to support greatly. In addition, I think they're also looking at issues that would have arisen simply rolling up, expanding NHIN along the lines that it was originally scheduled to, that is, from a dozen participants to a few hundred participants, which has to do with what are the interactions between the various components of agreements for usage and reciprocal service and standards. How are the standards adopted? What assurances are made that individual entities or service providers are able to conform to the standards?

Deven McGraw - Center for Democracy & Technology – Director

Yes. This is Deven. I've heard it described as a difference between NHIN as a network of networks versus maybe "N win" (NW-HIN) or somebody pronounced it "new win" at the policy committee. Whatever we want to call it, the new vision of a national network is a set of standards and policies that are used in health information exchange, not whether you're participating directly or participating through a network.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I just want to say, I actually think this conversation is a little bit confusing. I don't think that the network issue actually changes with the definition. The Internet is a network of networks, and the NHIN, as it's been defined, and as it's currently defined, is defined as the standards, policies, and services to share information with privacy and security over the Internet.

I don't think it's so much a network issue. I, quite frankly, am totally confused about the different definitions, even listening to different people today. What I understood was that there is an effort to try to rename certain elements of the work that's going on now. I guess I would just ask that we get maybe some clarification from ONC about the definitions because, even listening to this, I'm totally confused.

Paul Egerman – Software Entrepreneur

Go ahead, David.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

It's Wes.

Paul Egerman – Software Entrepreneur

Go ahead, Wes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Since what I said was called into question, let me try again here. There is a set of policies, procedures, and an operating organization that was established under the NHIN trial implementations, a policy and agreement approach that established the DURSA, and that was for the scope that I described. Until last February, that was all that was ever described as the NHIN. As of last February, the scope was greatly expanded. I'm not saying that it was a bad idea. I'm just saying it's what happened and that this sort of going in assumption that this was just making legal what would have otherwise not been legal, which is to simply expand the old approach to entities other than those that have contracts with the federal government, that notion that it was going to be that simple was what didn't pan out in the start of this group of this effort.

Paul Egerman – Software Entrepreneur

This is Paul. These are helpful comments, and certainly a piece of feedback that might be taken back to the governance group is some clarity on this issue because I agree with Carol. After hearing all this, I don't quite have my arms around what this is all about. When I said that the difference between NHIN and NW-HIN was the W, actually that's what I thought it was. I didn't realize that they had made this distinction or the distinction had been made. I had noticed that John Lumpkin talked about something I think Wes said also that this is really governance among exchanges, and I'm concerned about that because it does include a directed exchange model. It needs to be governance also when there's not an intermediary involved. That's one comment.

The other comment that I would tell the tiger team that I had made during the policy committee on this issue was, as we heard, after we heard from governance, we also heard Micky Tripathi talk about entity level provider directories, which is sort of like the title describes what it is. It's a directory at an entity level of providers that are participating in an exchange. And when Micky did his presentation, he had a type of organization that he called a registrar, which would be responsible for somehow either registering people in the directory or monitoring these directories. And so the observation I made is the function that he called a registrar could possibly be related to the function that the governance committee is calling a validation function. And that the directory itself could be used as a governance vehicle in the sense that if you wanted to remove somebody from the NW-HIN, you could simply remove them from the directory. Our recommendation also could be on provider authentication, possibly could be a governance vehicle, which is, you could refuse to either renew or possibly revoke a digital certificate under some circumstances. Those are my observations.

The other observation I made that caused a little bit of comments afterwards is, I said, well, maybe this validation approach should just be very objective. Does the entity meet the technical requirements? How much effort is going to be put into making sure that they actually are abiding by various policy, privacy policy rules in an affirmative way as part of the validation process? That struck me as difficult and possibly duplicative in terms of other accreditation things that may be going on. Those are my observations. I don't know if they make any sense.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

This is Wes again. It really gets down to not having – having recognized through a discussion that we don't have an agreement on the term governance, or we'd like to maybe cater it in a way that it's typical than it's used. One of the participants of the team said with some resonance, why would you call it governance if you can't govern or if you don't have an organization to govern? That is, initially, if this is nothing but another group issuing regulations, policy, and certification criteria, it's not governance in the sense that a lot of people thought it was and that it was originally addressed in the prior effort. I think there's a lot of opportunity for clarification there.

Judy Faulkner – Epic Systems – Founder

Wes, if you issue the regulations, and if you make up the regulations, isn't that governance...?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

That's governance in the sense that that's what governments do, right? The question is, do you have the...?

Judy Faulkner – Epic Systems – Founder

Anybody to enforce it?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes. Right.

Judy Faulkner – Epic Systems – Founder

You're saying, must make the rules and enforce it, and they're missing the second part.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

No. Most of the time there are two uses of the term governance. One is it's what governments do. The other one is that it has as specified scope of participants, and I may be off base here, but my thought is that that's different than simply issuing regulations. When the credit card associations issue governance, they are specifically saying, if you want to participate in this network, this is what you have to do.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

And here's how we test, whereas, under the current definitions, the NHIN is not a network. That is, it's a set of policies and procedures for building a network, but there is no identified thing, and that's very deliberate, very deliberate on the part of ONC to make it that way, so it's hard to say, well, what are the levers that you use? This has really turned into a microcosm of the entire range of issues that the policy and standards committees are addressing.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Eggerman – Software Entrepreneur

I'm sorry, Deven. Were you going to say something?

Deven McGraw - Center for Democracy & Technology – Director

Well, I was going to say, I think that's right because if you look at – I don't want to belabor the point, but I think a lot of the other groups that have been established under the policy committee or the standards committee have been dealing with the substantive issues of what should the policies be, or what should the technical standards be, whether it's for the EHRs or the behavior of the entities and persons who are using and exchanging using the EHRs. But it's dealt with the what, and so I think running through a lot of these conversations is, once you've decided the what, how do you make sure that you set of actors who are complying with those sets of policies? There are sort of various levers that we know exist at the government level, but are they enough? Is that going to work from an implementation standpoint? And if we think it's not enough, then what are the additional steps that need to be taken? I don't know if folks agree with me, but that's sort of the bigger picture view that I have of why you would establish, why you would need to think about governance at all....

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes. Deven, this is Carol. Reflecting on this a little bit, one of the things I wanted to say that I think has implications for our work is that I worry with some of the recommendations that maybe we stop too short of giving that enforcement and oversight element or validation, whatever you want to call it, not enough attention. Even on the issue of provider authentication, there are several levels at which you would want to have a policy discussion about where enforcement happens and where transparency exists. It's not just if you issue credentials and someone abuses them that there are enforcement issues, but it's also the question of if an issuer of those credentials issues them in a way that doesn't comply with strong requirements. What happens to them?

In other words, there are enforcement issues at multiple levels, and I just want to reflect on this. I'm not saying we have to work through every element of enforcement and validation, but I think our

recommendations and something to keep in mind would benefit from just taking the requirements of those recommendations in terms of oversight and enforcement a little bit further than we have because I think the governance discussion is simple when it's in general terms, and it starts to get extremely complicated when you start talking about it in a way that applies to both something like provider authentication and, let's say, patient matching or whatever. These are going to be very different elements, and they're going to require very different conversations about validation.

Paul Eggerman – Software Entrepreneur

Those are great comments. I just want to be....

Deven McGraw - Center for Democracy & Technology – Director

Good point, Carol.

Paul Eggerman – Software Entrepreneur

Those are good comments. I also want to be respectful of people's time on the agenda. We probably should be moving on to talking about the patient matching here.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Eggerman – Software Entrepreneur

But does anybody have anything else they want to say on this topic before we move on that perhaps hasn't spoken?

Judy Faulkner – Epic Systems – Founder

I'd like to just add a little bit more to the HIT policy committee meeting. This is Judy. Which is, I do think we spent a lot of time on it, which is not bad at all, focusing on how do we tighten up what people already do, tighten up stuff that we send to lab, tighten up stuff that we send to other places. This was different groups in the meeting. But I think I mentioned that my concern was when we leave what we normally do and go into what isn't as common.

In other words, what we're trying a lot to do right here, which is one healthcare organization to another, is to me the variation from what we do electronically already because right now we do that just on paper. That is going to move to electronic, so that's a new one. To me, that sort of stuff needs a lot of attention.

Then the other thing is we talked a little bit about, which was sending this stuff to – sending information to organizations that are not business associates. And, from there, it could go into public instead of private access. I don't know what to do about that.

Leslie H.

This is Leslie. I just want to add that I think that governance is critically important and, however it gets handled, it may not be this committee, but it can't fall through the cracks.

Deven McGraw - Center for Democracy & Technology – Director

Yes. That's a good point, Leslie. Notwithstanding that the government's workgroup's recommendations, the policy committee was not ready to endorse them. I think that that's not at all the end of the conversation. They're going to be, as Carol mentioned, chunking them up into giving themselves more time to sort of drill down on specifics and teeing them up in sort of chunks of recommendations that might be easier to understand, might be easier to reach resolution on a smaller set of issues first. I don't think it's falling through the cracks at all, but it doesn't make it any less complicated.

Judy Faulkner – Epic Systems – Founder

Yes, it really is because, as an EHR vendor, what happens when you're being asked to send stuff to non-business associates who likely is going to send it elsewhere. You're right in the middle of those or even any legal liability. I just don't know what to do.

Paul Egerman – Software Entrepreneur

This is Paul. The comment you just made, Judy, is a comment I've heard from one of your colleagues at a different company. He has the exact same concern, which is, what happens as a vendor if I facilitate this?

Judy Faulkner – Epic Systems – Founder

Yes. Exactly, and some of the organizations at the other end who want to accept stuff are fairly large organizations. What happens when it goes into the cloud and does cloud computing? What are they doing it with? What about some other repositories? What are they doing with it from business intelligence? So there's a lot of stuff going on there outside of what we're looking at, to me, is kind of the monster lurking around the edges.

Paul Egerman – Software Entrepreneur

It sounds like the people on the governance committee have their work cut out for them.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

That's one way to look at it.

Paul Egerman – Software Entrepreneur

They have almost as big a challenge as we have, would be my guess. That's how big a challenge they have.

Judy Faulkner – Epic Systems – Founder

Doesn't this fall under privacy as well?

Deven McGraw - Center for Democracy & Technology – Director

Judy, it does, but as we've – and we've recognized all along that the lines, we've been drawing these lines in order to try to move these issues with a group of volunteers who have been very dedicated in giving up of their time, but can't be asked necessarily to take on everything, so we've sort of carved some of this stuff up into pieces to allow groups to move on it simultaneously. It doesn't mean that we won't occasionally be treading on each other's territory. We've tried to draw the line between what we do as a privacy and security tiger team and what governance does as the difference between the what and the how. But I think, with us doing the what, what are the policies, and governance thinking about how you hold people accountable to them. But as Carol mentioned, the enforcement piece is a critical function of privacy and security. And if you think of enforcement as both accountability, as well as substance, it just underscores the need for some overlap in membership, which is good, that we have, and always keeping in close contact with one another so that we're at least being consistent.

Judy Faulkner – Epic Systems – Founder

But if we make the rules, and they enforce the rules, then we need to add a focus on the rules for what happens with the non-business associates so that they can enforce it then.

Deven McGraw - Center for Democracy & Technology – Director

That's right, Judy. We have certainly always had on a long-term agenda the issue of personal health records in particular not covered by non-HIPAA covered entities. Two things: one is that the Office of the National Coordinator, ONC is hosting a roundtable on non-HIPAA covered entities in early December on this very issue. They are required to do a report to Congress on this issue. We have put some other issues on our agenda higher up because there's already work being done on this issue gathering public input.

Then, secondly, with respect to who has jurisdiction over non-covered entities, HHS doesn't have any jurisdiction at all over those entities, and this is in fact also bumping up against efforts by the Federal Trade Commission to think about its authority under the Unfair and Deceptive Trade Practices Act for Internet companies. In some respects, I understand that this is of great concern to covered entities, sharing data into the non-covered entity space, whether it's cloud based or non-cloud based. But I think we have a lot of issues. I disagree that there are no issues associated with the covered entity space

exchange, and given the amount of activity and the limits of HHS's jurisdiction over non-covered entities, we have put a few other things higher up on the priority list, but that piece has always been on a longer-term agenda.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Deven, this is Wes. Sorry to always have the same hand up in the back of the class, but I've had a major ah-ha in this discussion, which is that governance is where the rubber meets the road, so that everything going on in almost any committee is at least theoretically a governance issue.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

There is also a smaller set of issues that are probably not being addressed anywhere else or at least are only being addressed tangentially other places. It's probably if we think about the governance committee more explicitly in terms of overlaps rather than saying, well, we just have to deal with that somehow, we might come up with a more focused approach.

Deven McGraw - Center for Democracy & Technology – Director

I'm all for a more focused approach. If you want to send some more concrete stuff in terms of what you're thinking, Wes, I would certainly. I mean, I truly value the time that all of you, and Paul and I as well, are putting into this. If we can find a better way to move, a more effective way to move this forward in working in tandem with other groups, I am all for it. I would love to hear more about that.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

You're asking me to go beyond blathering to specifics, and that's always a challenge, but I'll try.

Deven McGraw - Center for Democracy & Technology – Director

Yes. We don't have to do it on this call. If you want to spend some more time thinking about what that might look like.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Sure. I'd love to.

Deven McGraw - Center for Democracy & Technology – Director

We could do that offline.

Paul Egerman – Software Entrepreneur

It's a great discussion. Are we ready to move on to the patient hearing?

Deven McGraw - Center for Democracy & Technology – Director

I think so. Yes. We have a patient matching hearing scheduled for December 9th, and I sent out this sort of current description of the scope, which we had worked on, as well as the list of potential witnesses. We're in very good shape. I just want to pull it up here.

Paul Egerman – Software Entrepreneur

Yes. Can we pull that up, Judy? Is that one of the things we could pull up on the...?

Deven McGraw - Center for Democracy & Technology – Director

No, it's not on a slide. The document is, if you look at your downloads, there's a patient matching hearing C84 kilobyte size document on the left. But it's not in slide format, so it in order for it to be up on the screen, they'd have to shift.

Paul Egerman – Software Entrepreneur

They have something.

W

You want to share the agenda for the hearing?

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes. I sent them....

Deven McGraw - Center for Democracy & Technology – Director

If you can, actually, that would be great.

W

Yes, I can bring that up. Give me just a second.

Deven McGraw - Center for Democracy & Technology – Director

All right. Terrific. That's good. If you work through these panels, we still have a couple of holes to fill, but not many, which is good.

Paul Eggerman – Software Entrepreneur

Perfect.

Deven McGraw - Center for Democracy & Technology – Director

Great. Very good. Now I lost my screen. Here we go. We have, for panel one, we have Barbara Dempster from HIMSS, Scott White from Kappa Kappa Psi. This is the, what is the problem? Why do we need accuracy? We have confirmation from Dempster, White, and Sean Grannis. We haven't heard yet from Ken Beutow, but I suspect that's because his schedule is so cramped, so I will definitely be getting in touch with him this week. But we may need somebody else from the research community if it turns out he can't do it, although I suspect he will have someone to suggest if he is not able to come.

And Garland Land, who is with the National Association for Public Health Statistics and Information Systems, that is a locally based organization, but he is actually lives in the state of Missouri and has asked if it would be possible for him to testify by phone. He's the only one of the panelists who has asked that, and so I wasn't sure how we felt about that. I told him I would get back to him. He did try to get the person from the state of Maryland, who is much more local, but unfortunately she cannot. She has a conflict on that day and cannot come.

If we scroll down to panel two, this is, we have two solutions panels that are from the healthcare sector. This is the first one. What are the solutions used by these various actors? We have Linda Fischetti coming from the VA. I think she's confirmed. Right, Judy?

Judy Sparrow – Office of the National Coordinator – Executive Director

Either she is coming, or she will find somebody for us, yes.

Deven McGraw - Center for Democracy & Technology – Director

Terrific. From the health plan side, we have Paul Oates, who is the senior enterprise architect for Cigna. We have Dr. Scott Shoemaker, who is the chief scientist, IBM Software Group. Some of you may know him better as the chief scientist for Initiate that works on algorithmic matching. They were purchased by IBM not too long ago. Then Rich Elmore from AllScripts, to bring the vendor perspective, and we had asked - was this the panel that we had asked for? See, my other document works a little better. Sorry about this, because I know where the holes are. We also have - okay, maybe this is it for this panel, can we scroll down on panel three? Great. So this is the second solutions panel, which we have scheduled for after lunch. We'll have someone coming from SureScripts. They're trying to sort that out. Ken Tarkoff from RelayHealth, Sean Nolan from Microsoft, and then we had asked Martin Harris from the Cleveland Clinic, but he is actually not able to come. So that actually does give us a hole to fill, somebody from a healthcare institution or organization side.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Can we scroll up to that for one second again, please, just for a second?

Deven McGraw - Center for Democracy & Technology – Director

Yes, scrolling back up?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes.

Deven McGraw - Center for Democracy & Technology – Director

Okay, can you scroll up, are you seeing what you need to see?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes, thank you.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Are we going to be able to get a copy of this to print?

Deven McGraw - Center for Democracy & Technology – Director

You did.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Oh, okay.

Deven McGraw - Center for Democracy & Technology – Director

I sent it out on Friday.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Oh, okay, thanks. I probably have it in front of me here.

Paul Egerman – eScription – CEO

Deven, I get the sense we have to think of how to replace Cleveland Clinic.

Deven McGraw - Center for Democracy & Technology – Director

Yes, we have to replace Cleveland Clinic. And then in the last panel, if you can scroll down again to panel four, this was where we were looking for approaches in other industries. We had asked Patricia Cogswell from DHS. She is not able to come because she's changing jobs within DHS, but she got us someone else. We have Lyn Rahilly, who is the Privacy Officer for the Department of Immigration and Customs Enforcement, ICE. I had a good conversation with her on Friday.

From the financial side, we have somebody coming from Fair Isaac that MITRE had helped us to get. And initially, we were going to reach out to—I actually did reach out to the folks who do matching for our market research purposes, I sent an e-mail to see if they would be interested in testifying. I wasn't entirely surprised that I didn't hear back from them. I think in the market research context, maybe they are, I don't know, I will keep trying to get a hold of them.

But it also occurred to me that the accuracy level that is required to match people to data from a market research perspective, may not be as high as we would want it to be in healthcare, and that we might think about an industry where it's more critical for the match to be right and do the outreach there. You can get

it partially right and still be successful from a marketing perspective, but partially right, it doesn't work in healthcare.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Have you thought about asking somebody like Initiate, which is an IBM company?

Deven McGraw - Center for Democracy & Technology – Director

They're coming.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Why did I not see them?

Deven McGraw - Center for Democracy & Technology – Director

Yes, it's Scott Schumacher.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Okay.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Deven, I was going to suggest that maybe someone on this issue of is there another sector, maybe someone from the credit industry. I mean, one of the interesting things about the credit industry is that there is a level of transparency about identity. In other words, you have to make sure that the information they have about you is accurate and correct it.

Deven McGraw - Center for Democracy & Technology – Director

Right.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

And I'm thinking of the big three credit agencies.

Deven McGraw - Center for Democracy & Technology – Director

Right.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

And they obviously are amassing information from lots of places to come up with a credit score. So that may be an area to look at.

Deven McGraw - Center for Democracy & Technology – Director

That's a great idea.

W

Deven, this is Alison from MITRE, FICO Fair Isaac, they are one of the credit reporting bureaus.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes, that's

Deven McGraw - Center for Democracy & Technology – Director

Okay.

Paul Egerman – eScription – CEO

Okay.

W

I had never heard of Fair Isaac...

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I thought they were not available.

Deven McGraw - Center for Democracy & Technology – Director

Yes, I didn't think they were confirmed, but they are.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Oh, they are.

W

And they're more responsible for your credit score.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes.

Judy Faulkner – Epic Systems – Founder

Because they work with Equifax, right?

Deven McGraw - Center for Democracy & Technology – Director

I don't know.

W

There are three, there's Equifax, TransUnion, and FICO. Those are the three bureaus that are credit history reporting bureaus.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

But Fair Isaac is confusing, because they're also a vendor of rules engines and things like that, technology as opposed to the specific business service.

W

Yes, like...

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

A credit rating, yes.

W

Yes, I agree.

Deven McGraw - Center for Democracy & Technology – Director

That's correct.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I have to drop off the call now, folks, so it's been nice talking to you.

Deven McGraw - Center for Democracy & Technology – Director

Okay, thanks, Wes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Goodbye.

Deven McGraw - Center for Democracy & Technology – Director

Does anybody have any suggestions for a replacement for the Cleveland Clinic representative?

Paul Eggerman – eScription – CEO

There's the issue that we have to replace Cleveland Clinic or should we get somebody else from Cleveland Clinic other than Martin Harris, or is he the person you want to ask, that you want to have the top person, so we should replace the whole organization?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I had a question about that too, because the challenge with a lot of these hearings is that we end up with a lot of people and a lot of testimony to get through. I was wondering if someone like Shaun Grannis could fill some of that role at Reagan Street. I mean, I'm happy to have another sort of large system, but I feel like between some of these other vendors and Reagan Street, maybe we cover it, I don't know.

Judy Faulkner – Epic Systems – Founder

The value of the healthcare organization is that they everyday have to do this stuff.

Paul Eggerman – eScription – CEO

That's right.

Deven McGraw - Center for Democracy & Technology – Director

Well, right, but I think that, yes, I mean, but that's why I think, Carol, am I right in that they have to do this at Reagan Street.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Oh, yes, yes, absolutely.

Deven McGraw - Center for Democracy & Technology – Director

Right, that is why we were sort of reaching out to more than one healthcare organization quite frankly, but we're not wedded to have a fourth person. But certainly, if anyone wants to suggest somebody, let us know.

Judy Faulkner – Epic Systems – Founder

Okay.

Deven McGraw - Center for Democracy & Technology – Director

In terms of whether it's someone else at Cleveland Clinic, I think we particularly asked for Martin Harris. One, because of the stature of Cleveland Clinic, but also that he is very well-known for being someone who knows something about this issue and who's talked about it was my sense when we ...

Judy Faulkner – Epic Systems – Founder

I would say if you want another person at Cleveland Clinic, you could try for Pam Piar, who's the Senior Executive of IT, or you could do someone like Daniel Barchi, who was the CIO of Carillion, is now the CIO of Yale.

Paul Egerman – eScription – CEO

This is Paul, the last one you said, Judy, is interesting to me, only because one of the things we're trying to do also is to get people in the organizations involved, who have not been involved before. I don't think we've had anybody from Yale.

Judy Faulkner – Epic Systems – Founder

Yes, he's new at Yale, but he recently left Carillion.

Paul Egerman – eScription – CEO

That's a good suggestion.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

However, it might also be interesting to see what some of those organizations are using. And the reason why I say it that way is, like UPMC is using Initiate for all of our patient matching.

Deven McGraw - Center for Democracy & Technology – Director

Right.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

If you could find the underlying companies that are providing the services or the technology or tools, it might be as informative to have them come in and discuss them as any particular organization like a Cleveland Clinic or a Yale.

Judy Faulkner – Epic Systems – Founder

Here's another one you could use, Bryan Wolfe, his position, he's the CIO of CHOP, which is children. So that would give you a...

Paul Egerman – eScription – CEO

Children of Pennsylvania?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Philly.

Judy Faulkner – Epic Systems – Founder

Philadelphia.

Paul Egerman – eScription – CEO

Of Philadelphia?

Judy Faulkner – Epic Systems – Founder

Yes, that's a very prestigious children's group.

Paul Egerman – eScription – CEO

Yes, I've been there and it is a great group.

Judy Faulkner – Epic Systems – Founder

Yes.

Paul Egerman – eScription – CEO

That's where ... used to practice.

Judy Faulkner – Epic Systems – Founder

I'm looking for things on the east coast, so they don't have too far to go.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

This is Dixie; one of the organizations that I'm surprised you don't have is CMS.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

What about the VA or is the VA—

Paul Eggerman – eScription – CEO

The VA is here.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

VA, but CMS has one of the biggest challenges of the organization I know in this area.

Deven McGraw - Center for Democracy & Technology – Director

It's funny, Dixie, I know CMS came up in our discussions, but I don't know why they didn't end up on this list, maybe because we have the VA, I couldn't even say though. And we have a national health plan.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes, but—

Judy Faulkner – Epic Systems – Founder

I think it's good to get both government and nongovernment, because—

Deven McGraw - Center for Democracy & Technology – Director

Absolutely.

Judy Faulkner – Epic Systems – Founder

Yes, because government can—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

We have primarily nongovernment right now. And you would think we would have the largest government payer.

Deven McGraw - Center for Democracy & Technology – Director

Okay. Well, those are good suggestions.

Joy Keeler – MITRE Corporation – Health IT Program Manager

This is Joy; before you put CMS on there, I think we should do a little exploration as to whether CMS just relies on social security numbers.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Joy Keeler – MITRE Corporation – Health IT Program Manager

Because if that's the case, I don't know that having them participate is going to move the ball forward.

Deven McGraw - Center for Democracy & Technology – Director

You just reminded me of the reason why, it's worth a discussion, but I think we assumed that that was the case.

Judy Faulkner – Epic Systems – Founder

Two more names I'll give you, one is Jon Burns, CIO at University of Maryland.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Judy Faulkner – Epic Systems – Founder

And the other is Marshal Ruffin, MD, at the University of Virginia. All within close enough distance to you guys, to DC, that it shouldn't be too hard.

Deven McGraw - Center for Democracy & Technology – Director

Yes, thank you, Judy.

Paul Egerman – eScription – CEO

Okay, thanks, Judy.

Deven McGraw - Center for Democracy & Technology – Director

Thank you very much for the suggestions.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Let me ask you, Judy, this is John Houston, what other vendors does Epic typically deal with from a patient matching perspective?

Judy Faulkner – Epic Systems – Founder

I don't know which vendors we use. And I don't know if we do. I thought that was interesting when you mentioned that, because I don't know that our customers do in the whole.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Initiate has a huge percentage of the market in patient matching. I mean, Initiate/IBM.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

We used to use Eclipsys awhile back, but I don't know where they ever went with their product.

Deven McGraw - Center for Democracy & Technology – Director

Allscripts have bought them recently, and we do have Allscripts coming.

Paul Egerman – eScription – CEO

Yes, that's correct. This is helpful to have these names. I'd like to turn this discussion a slightly different direction, which is to sort of think through the hearing, and to try to understand how we can make sure that we maximize our opportunity here; that we learn everything we can from this group of people and we manage the hearing correctly. And I'm just curious if people have any ideas as to what we should and shouldn't be doing in terms of making sure this is a very effective hearing.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I may have missed it, but do we have a set of parameters or questions drafted yet?

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Eggerman – eScription – CEO

Yes, we do.

Deven McGraw - Center for Democracy & Technology – Director

That went out with the documents.

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes, that went out and I've asked for a testimony to come back by December 2nd.

Paul Eggerman – eScription – CEO

Right, so we're going to get written testimony from everybody December 2nd. What Judy sent out was a request that they answer the questions and they prepare no more than a five-minute talk. My experience of other hearings is most people will do what you ask them to do. Some people will come in with their prepared materials a little bit later than December 2nd.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

Paul Eggerman – eScription – CEO

And although, there's sometimes good reasons. I spoke to one of the presenters who told me that anything he sends out has to be approved internally before he could send it out. So the December 2nd gave him a little bit of a challenge, because he had to write it, and then he has to get his approvals before he can send it out. And I guess I can understand in large organizations why that may be. But anyway, we're going to get the materials, most of it by December 2nd. I assume that we're going to get a few stragglers afterwards, and then we're going to have the hearing on the 9th.

One of the ideas that I had put forward, I had seen a hearing that Aneesh Chopra ran, where he sat the people down and said, "I know everybody prepared a five-minute talk, but I'm just going to ask you questions. We'll skip the talk," he said, "I'm going to run an audible." And he didn't let anybody do any presentations at all. It was all questions, and he asked good questions. And I thought it was a great panel, because we had an opportunity to listen to what people had to say. Because sometimes when they read their five-minute presentation, it like puts me to sleep at times.

So I put forward that as an idea, when I put forward the idea, somebody said, "Well, gee, the problem is, we as tiger team members won't have very much time to read their stuff, because we're not going to get it in a week or less prior to the hearings." What do you think about that?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

I like the idea.

Deven McGraw - Center for Democracy & Technology – Director

Yes, as I mentioned to you, Paul, this is Deven, I like the idea. Because the interactions of the panelists and sort of focusing them on the points that we want to make sure get addressed is imminently more palatable than just asking them to sort of read their testimony. I'm not sure; I mean, we have seven questions on the list for the testifiers. And presumably, we'd love to, if we had all of them address all seven, it would definitely take too long.

On the other hand, it's kind of hard to know in advance who should address which question most effectively. So I'm not—

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Can I ask a question, Deven and Paul?

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Coming out of this hearing is there a particular set of recommendations that you envision us making? The reason I'm asking that is because one thing that's been helpful I think for us in the past has been to try to make our recommendations in the context of what's required for meaningful use within a certain timeframe, so stage one or stage two or whatever. And the kinds of problems that that raises; and therefore, the questions can be more specific about the level of matching and accuracy and what have you in the context of those specific needs. Do we have that in mind or is this just a general set of recommendations?

Paul Eggerman – eScription – CEO

No, there were three questions in the materials that were sent out, that the tiger team is supposed to answer, Carol. And the three questions are - I'm doing this from memory, so someone is going to correct me if I've got it wrong.

Deven McGraw - Center for Democracy & Technology – Director

I have it right up on my screen; I'll help you out if you want.

Paul Eggerman – eScription – CEO

Right. The first one is sort of like, what is the accuracy that's needed for patient matching—

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

Paul Eggerman – eScription – CEO

—what level of accuracy? The second one is what standards if any should be determined for a patient matching? And the third one is what best practices that we finish? So those are the three broad questions.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Alright, I thought I saw those, Paul, and there is a document as well. The question I'm asking is these are sort of not context specific. In other words, the accuracy of patient matching inside of an enterprise for a particular sort of clinical service is one way to think about that question. And another way to think about that question is in the context of exchange. And another way to think about that question is in the context of quality reporting for meaningful use.

And I'm just wondering if we have more specific boundaries or parameters in mind, because I don't take it that our task is to make recommendations for matching that happened inside of a particular enterprise, correct?

Paul Eggerman – eScription – CEO

That's correct. This is Paul, I think that's correct. I think you're asking a good question, Carol, my top of the head answer would be that we would be primarily focused on information exchange based on stage one and what we hope to, we imagine stage two and stage three will be.

Deven McGraw - Center for Democracy & Technology – Director

Yes, this is Deven, I thought we made the point in earlier discussions about this hearing that for clinical treatment purposes that it's critical to have the right data in the patient's record internally, because if it's bad data that's going out, you've got to get it right on the inside before you can get it right on the outside. I thought that was a point that we made. But definitely focusing maybe more on the clinical exchange of data for patient treatment, which is very much in mind for stage one versus maybe some of these other secondary uses where the accuracy level may not need to be as high.

Does that make sense? I mean, that's why I'm struggling a little bit. We did in fact contemplate that internal data issues were needing to be resolved. I mean again, if the data isn't in the right file to begin with, we can't hope that it will be right, it does get corrected on exchange necessarily.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Right, that's absolutely true, Deven. And when we worked on the common framework, one of the things that was very clear was that if an entity could not accurately link its own records, it wasn't ready for exchange. Exchange isn't the place to solve that problem. But I still would ask whether our scope could be refined a little bit in the sense that we have some specific, I don't want to say use cases, but requirements of meaningful use that place some boundaries on this. Because I am not sure that simply focusing on this in a very general way is going to get us there. I don't know, I could be wrong.

Deven McGraw - Center for Democracy & Technology – Director

Yes, I think at a minimum, the types of data uses, the purposes for which data is accessed, used, and disclosed for stage one in meaningful use, which includes treatment care coordination, some quality and public health reporting ought to be sort of the initial focus.

Paul Egerman – eScription – CEO

Yes.

Deven McGraw - Center for Democracy & Technology – Director

I think that makes sense. I mean, that's always sort of where we've started in order to help ourselves come up with recommendations.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

Deven McGraw - Center for Democracy & Technology – Director

And it happens to be timed well to the sort of staged approach to exchange, but it's contemplated as part of meaningful use. So I do think it's helpful to think of it as a threshold matter.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, and that context—

Deven McGraw - Center for Democracy & Technology – Director

But we want to get there first.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

And that context might be very helpful for the testifiers as well.

Deven McGraw - Center for Democracy & Technology – Director

Yes, that's a good point.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Because they may all come at it from a different vantage point.

Deven McGraw - Center for Democracy & Technology – Director

Right.

Paul Eggerman – eScription – CEO

Those are good comments, Carol. This is Paul; it is an issue that we're going to have trouble with, because even the concept of information exchange, the way in which we define it, is not the way a lot of people will look at it.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Right.

Paul Eggerman – eScription – CEO

But that's the way we define it, if it goes from one entity to another entity, however a lot of people look at it if it goes from one of their hospitals to another of their hospitals or from their medical group to their hospital. And then sometimes that isn't really information exchange, but in some settings it might be pretty close, because those systems might be on totally different computer systems, and sometimes they're even in different states. So there is something to be learned from that discussion. It's an interesting challenge.

So what do we need to do with this challenge, do we need to be a little bit more focused in our questions?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

This is David, one thought occurs to me is that the demands for accurate matching aren't that different across those different scenarios or settings, but the remedy for an unclear match is likely to be quite different. And we may want to focus as much as we can on how do you deal with things that aren't a perfect match?

So for example in directed exchange between two physician offices in the same city, a simple phone call is usually sufficient to clarify any confusion about who the patient is. But if you're doing a nationwide health information network exchange across the country between two exchanges, it's going to be a very different process.

Paul Eggerman – eScription – CEO

Okay, that's valuable. And so—

Deven McGraw - Center for Democracy & Technology – Director

Yes, one thing we can do, Paul, is just to, one, focus our questions as a team, but also to let the testifiers know that the stage one meaningful use trend, the types of those data access and exchange capabilities that are contemplated for stage one will be a foremost thought in our mind.

Paul Eggerman – eScription – CEO

So how do we do that, should we send them an e-mail in advance saying these are the things we're thinking about to make sure you understand?

Deven McGraw - Center for Democracy & Technology – Director

Yes, Judy, does that sound right?

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes, that'll be fine.

Deven McGraw - Center for Democracy & Technology – Director

Okay.

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Not that they would necessarily listen, but yes.

Judy Sparrow – Office of the National Coordinator – Executive Director

It gives them a heads up.

Deven McGraw - Center for Democracy & Technology – Director

It gives them a heads up that's all.

Paul Egerman – eScription – CEO

So Deven and I will sort of draft that, and we'll probably get the e-mail addresses from Judy, and we'll send that out in the next few days. I'd like to return to my question about the five minutes of opening statements from these people; do we still want to do that? Do we want to shrink them down to three minutes? Do we want to say no opening statement and just do questions? How do we want to handle that?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Can I suggest, this is John Houston, that an alternative might be that if there are some very specific questions or there are specific questions that we want to tee up for discussion, then maybe you give them context for opening comments; like you say, here are the three questions that we have an interest in really understanding from this panel. If you'd like to discuss this prior to open questions, feel free. It sort of keeps them away from the prepared comments.

Paul Egerman – eScription – CEO

And what would be those questions?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Well, I don't know, we would have to come up with those questions. But I think it at least tells them what our thinking is in terms of where we want them to focus any opening comments.

Paul Egerman – eScription – CEO

That's a great comment, John. So I think we could be most successful with this hearing if we think about it as much as we can in advance, and think about what are the questions we want them to answer. And what are those questions besides the ones we've already posed to them?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

This is Dixie; I sort of have a slightly different view on that. I think that if they really understand what the hearing is all about, and they've gone to the trouble of coming to testify, I think they almost deserve five minutes of saying what they think about the topic. I also think that if we really make sure that they understand what we're driving at, they may come up with comments and observations that we may not

have even thought of in our questions. So I like the idea of giving them an opportunity to really express their thoughts about the challenges in this area.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

This is John Houston, my concern is of having heard years of testimony, it seems like about 50% of the time you get people that really do, do just that, and the other 50% talk about stuff that's either not on point or the most basic that is far beyond what you would have expected them to speak to.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes, that's a risk, yes.

Paul Eggerman – eScription – CEO

Yes.

Deven McGraw - Center for Democracy & Technology – Director

So I don't think we...

Paul Eggerman – eScription – CEO

I agree with you, John, but there's yet another 50% that also gives an elaborate description of how the organizations invest in the world ... We know these are great organizations, but—

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Exactly.

Paul Eggerman – eScription – CEO

I could never - I lose my patience for that.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes, but we can communicate that that's not what we want.

Deven McGraw - Center for Democracy & Technology – Director

Yes, this is Deven, I think ultimately, I've actually participated, and probably a lot of the rest of you all have as well, in both types of information gathering exercises. And one where you actually get five minutes to say what you want to make sure to convey, what you are interested in conveying. And then there's the panel piece where a type of arrangement where it's strictly answer the questions that are posed to you when you're on a panel, and there's always going to be some people who are scene viewers or take up more than their fair share of time in answering. And it's a little less satisfying, quite frankly, to be just a panelist, because you often don't get a chance to make the points that you wanted to make; or you're required to be more aggressive than you're necessarily comfortable with in some circumstances to get them made versus it's a lot more interesting as a viewer to watch those panels, because the interplay is interesting.

I think the advantage of the five minutes and strictly five minutes, and sticking to it so that people don't eat up their time with organizational descriptions, can help to cut down on some of the grandstanding for lack of a better word. But it does give people a chance to, we've asked them to come, we've made them prepare materials, give them the chance to make sure they get their points in within a short period of time, and then using the rest of the time for questions. It's an old formula, but I think there's a reason for it.

Paul Eggerman – eScription – CEO

Okay, we'll stick with that formula.

Deven McGraw - Center for Democracy & Technology – Director

But it does underscore like letting people know that given the amount of time that we have and the desire to really get into some back and forth with the panelists on the questions that we are really going to be strict with people about the five minutes. And then of course, we have to do that, which is not an easy thing to do.

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes, I actually have a little timer we can put right up on the screen, so they can see it, five minutes.

Deven McGraw - Center for Democracy & Technology – Director

Great.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I think that's always very helpful, Judy.

Paul Eggerman – eScription – CEO

Okay. Are there any other comments as to what we can possibly do to try to make sure that this hearing is as useful and successful as possible?

Deven McGraw - Center for Democracy & Technology – Director

Yes, us taking the time to read through testimony that we get in advance, it's a tall ask, but that would probably be helpful.

Paul Eggerman – eScription – CEO

Okay, I agree, if everybody could do their best. We're going to put you in a tough situation that you're not going to have a lot of time between the time you get it until the hearing. But I think Deven's request there, if everybody could do their best to read through it.

Deven McGraw - Center for Democracy & Technology – Director

Well, right, and I'm putting that on myself as well. And also we have an interesting ... to position of a tiger team call the day after this hearing, which will allow us to have a discussion about what we heard the day before when it's really fresh in our minds. This is an FYI, hearing on the 9th and tiger team meeting for two hours on the 10th.

Judy Faulkner – Epic Systems – Founder

So Deven and Paul, who are you expecting from this group to show up there? Should we all be planning to show up?

Deven McGraw - Center for Democracy & Technology – Director

To the hearing or to the call?

Judy Faulkner – Epic Systems – Founder

To the hearing.

Deven McGraw - Center for Democracy & Technology – Director

Yes, I had expected people to come in person; you are allowed to come in person. If it's hard for you to come in person, then obviously you can be on the phone.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Are there travel dollars for it?

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes, we do have travel funds, limited, but we do have them.

Paul Eggerman – eScription – CEO

How many people are planning to be there?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

You may want to do it by roll call.

Deven McGraw - Center for Democracy & Technology – Director

Yes, well, Dixie, I know you said that you had something else in DC, but you were going to be able to come over, but you'll already physically be here, right?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I'll be there in the afternoon.

Deven McGraw - Center for Democracy & Technology – Director

Okay.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

But I will be flying home on Friday.

Deven McGraw - Center for Democracy & Technology – Director

Okay.

Paul Eggerman – eScription – CEO

Okay. Carol, are you going to be able to make it?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I'm going to try. I have to move something, but I'm going to try to do it.

Paul Eggerman – eScription – CEO

David?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, I'm working on it.

Paul Eggerman – eScription – CEO

... are you still there?

Deven McGraw - Center for Democracy & Technology – Director

No, she had to drop off.

Paul Eggerman – eScription – CEO

Rachel?

Rachel Block – New York eHealth Collaborative – Executive Director

Unfortunately, I'm not going to be able to come.

Paul Eggerman – eScription – CEO

Okay. Alice?

Alice Brown – National Partnership for Women & Families – Director HITP

I will be there.

Paul Eggerman – eScription – CEO

You will be there, terrific. John?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

I plan to be there, yes.

Paul Eggerman – eScription – CEO

Okay. I guess Wes is off, Judy, are you going to be able to make it?

Judy Faulkner – Epic Systems – Founder

I'm giving you 50/50 on that one right now, I'm traveling overseas.

Paul Eggerman – eScription – CEO

Well, you can send Carl or a designate if you wanted to also.

Judy Faulkner – Epic Systems – Founder

Okay.

Paul Eggerman – eScription – CEO

That would be great. Did I miss anybody? Joy?

Judy Sparrow – Office of the National Coordinator – Executive Director

Leslie Francis?

Deven McGraw - Center for Democracy & Technology – Director

Leslie had to jump off.

Judy Sparrow – Office of the National Coordinator – Executive Director

Okay. Adam?

Adam Greene – Office of Civil Rights – Senior HIT & Privacy Specialist

I'll be coming in person.

Judy Sparrow – Office of the National Coordinator – Executive Director

Okay.

Deven McGraw - Center for Democracy & Technology – Director

I'll be there - this is Deven, of course, I'm local so it's not hard.

Joy Keeler – MITRE Corporation – Health IT Program Manager

Me too, this is Joy, I'm planning on it.

Paul Eggerman – eScription – CEO

Yes.

Judy Sparrow – Office of the National Coordinator – Executive Director

Good.

Paul Eggerman – eScription – CEO

And I'll be there, too.

Judy Sparrow – Office of the National Coordinator – Executive Director

And Gayle, I don't think is on the call, but we can find out.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Eggerman – eScription – CEO

So I think this is going to be pretty good attendance.

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes, it sounds like it.

Paul Eggerman – eScription – CEO

Terrific. Is there anything else about the hearing that anybody wants to discuss? I think we've got a good plan for it.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Eggerman – eScription – CEO

And before we open ourselves up to public comment, is there anything else any member of the tiger team wants to discuss?

Judy Faulkner – Epic Systems – Founder

Yes, just one thing I wanted to add. It was asked by John Houston I think, what our customers used for patient matching, what outside system?

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Judy Faulkner – Epic Systems – Founder

And I sent e-mails off to people. And the typical customer doesn't use anything outside.

Paul Eggerman – eScription – CEO

Okay.

Judy Faulkner – Epic Systems – Founder

They use their own software.

Deven McGraw - Center for Democracy & Technology – Director

Okay.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

And this is David at Cerner, that's similar for us, we just implement our own.

Paul Eggerman – eScription – CEO

Okay, that probably is happening that some customers might be on their own using some things.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, definitely for entities that aren't primarily EHR entities like exchanges, they use some third-party tool like Initiate.

Paul Eggerman – eScription – CEO

It's also the case for large organizations like you can see end up having systems from multiple vendors.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes.

Paul Eggerman – eScription – CEO

And so there may be other issues involved with some of those vendors.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right.

Paul Eggerman – eScription – CEO

So any other comments, any comments anybody wants to make on the tiger team on any issue?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

I'm good.

Deven McGraw - Center for Democracy & Technology – Director

Let's open it to the public.

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes. Operator, could you please see if anybody from the public wishes to make a comment?

Moderator

Yes, if you are on the phone and would like to make a public comment, please press star one at this time. If you are listening via your computer, dial 1-877-705-2976 and press star one to be placed into the comment queue. We do not have any comments at this time.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you.

Paul Eggerman – eScription – CEO

Thank you. And let me once again thank all of the members of the tiger team for your dedication. And so we want again to thank Judy Sparrow, Joy Pritts, Adam Greene, and the entire team for all of their help, and the people at MITRE.

Deven McGraw - Center for Democracy & Technology – Director

MITRE, too.

Paul Eggerman – eScription – CEO

And I want to wish everybody a Happy Thanksgiving.

Deven McGraw - Center for Democracy & Technology – Director

Yes, Happy Thanksgiving, everybody.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Happy Thanksgiving.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

You, too.

Judy Faulkner – Epic Systems – Founder

You, too.

Deven McGraw - Center for Democracy & Technology – Director

Thank you.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Goodbye.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thanks.

Judy Faulkner – Epic Systems – Founder

Goodbye.